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ABSTRACT

This document contains materials from a Congressional public forum which focused on multigenerational approaches to the health and economic problems of Americans. Introductory remarks are included from Fernando Torres-Gil, staff director of the House Select Committee on Aging; Victor Sidel, president of the American Public Health Association (APHA); and Pearl German, chairwoman of the APHA Gerontological Health Section. Anne Brushwood describes her experience of working to support her family while being the primary caregiver for three ailing relatives, and suggests ways of lessening the burden of care for families. Rosalie Kane, a University of Minnesota professor, discusses the interdependency of the aged and their families; the difficulties faced by families caring for a dependent elder; the impact of Medicare and Medicaid policies on the aged and their families; and priorities for reform. Jacob Clayman, chairman of the Leadership Council of Aging Organizations and president of the National Council of Senior Citizens describes how the health and financial needs of all Americans are interlocked and how actual budget cuts and those proposed under the Gramm-Rudman-Hollings Amendment jeopardize health programs for the young, the old, and the poor. A committee analysis of the impact of the Gramm-Rudman-Hollings Amendment on programs for the aged, children, and poor, and a report on multi-generational equity being prepared by the Gerontological Society of America are appended. (NB)

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[COMMITTEE PRINT]

PROTECTING AMERICA'S AGED, CHILDREN, AND POOR

MULTI-GENERATIONAL NEEDS MULTI-GENERATIONAL SOLUTIONS

A PUBLIC FORUM

PRESENTED BY

THE CHAIRMAN

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

IN CONJUNCTION WITH THE ANNUAL MEETING
OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

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TABLE OF CONTENTS

	PAGE
Table of Contents	iii
Foreword	iv
Introductory Remarks	
Fernando Torres-Gil, Ph.D. Staff Director House Select Committee on Aging	1
Victor Sidel, M.D., President American Public Health Association	3
Pearl German, Sc.D., Chairwoman Gerontological Health Section American Public Health Association	6
Panel Presentations	
Anne Brushwood Charlottesville, Virginia	7
Rosalie Kane, D.S.W., Professor Schools of Public Health & Social Work University of Minnesota	15
Jacob Clayman, Chairman Leadership Council of Aging Organizations President, National Council of Senior Citizens	28
Panel and Audience Discussion	35
Concluding Remarks, Dr. Torres-Gil	39
Appendix A: Gramm-Rudman Analysis	41
Appendix B: GSA Report	51

FOREWORD

For the past five years, older Americans and their families have suffered severe cutbacks in essential health and social programs. Added to this is the recent move toward a balanced budget that portends even further cuts at the expense of vulnerable Americans of all ages. What this reflects is a fundamental policy shift in this country away from programs for people and toward military spending and a tax policy that has put a greater burden on middle income families and their children.

Not only have older persons, "baby boomers" and children suffered as a result of this shift, but it has also led us to the point where myths such as intergenerational conflict can be confused with reality and take on a life of their own. This is the threat we are facing now with the frightening notion that the elderly are receiving an inequitable share of public resources and that this inequity will lead to conflict between the generations.

In truth, it is those who advance this notion of intergenerational inequity that may create a conflict where none exists. If we allow this notion to fester, it will only increase the vulnerability of Americans of all ages and distract attention from the real causes of the nation's deficit -- defense spending and tax reductions. **For America's elderly, their children and their grandchildren, the common stake of generations is a fact of daily life.**

What progress has been made to improve the health and economic security of older Americans has brought benefits to the elderly and their children, to whom they would otherwise turn for support. So too do programs such as Social Security, Medicare and Medicaid have multi-generational benefits. In the case of catastrophic illness and long term care, the elderly, their families and the young remain at high financial risk because of the lack of public or private protection against the cost of chronic care.

The declining poverty rate among elderly persons is not a sign that all is well with America's aged. Nor is the increasing poverty rate among children the result of "overspending" on the elderly. **It is a result of almost criminal neglect of our children and the dramatic cutback in programs that have served them well.**

At the same time, the median family income of elderly persons is still 42% less than non-elderly median family incomes and the percentage of poor elderly still exceeds the poverty rate of other adults. Added to this is the increased health-related financial risk of the elderly and their families that forces even middle income families to spend down to Medicaid when chronic illness strikes.

On November 20, 1985, the House Select Committee on Aging held a public forum to dispel this notion of intergenerational conflict and to call for multi-generational solutions to the health and economic problems of America's old and young alike. Presented in this report are the experiences and recommendations of experts in the health community and family members who face the burden of caregiving on a daily basis.

The forum was held in conjunction with the annual meeting of the American Public Health Association (APHA) and cosponsored by APHA's Gerontological Health Section. As such, the forum also an important statement on the shared commitment of health professionals, policy-makers and the public to programs that protect vulnerable Americans of all ages.

Two documents released at the forum are included as appendices to this report. The first is an updated Committee analysis of the impact of the Gramm-Rudman Balanced Budget Amendment on programs for the aged, children and poor. The second is a preview of a report on multi-generational equity being prepared by the Gerontological Society of America for release in early 1986.

Dismantling programs, such as Social Security and Medicare, that have been built to protect today's and tomorrow's elderly and their families is not the answer to inadequate protection of America's children. Nor is failing to complete the unfinished agendas for Medicare and Medicaid the answer.

In fact, we are facing a demographic challenge driven by the children of today's elderly, the "baby boomers," that will greatly increase the need for sound economic and health care programs in the future. **Myths such as intergenerational inequity and conflict threaten efforts to plan responsibly for this next generation of American elderly.**

It is the Committee's hope that the ideas presented in this report will be a challenge to those who advance the destructive notion of intergeneration conflict. **The issue is not whether one section of society has been protected at the expense of another, but whether the needs of all vulnerable Americans will be adequately met now and in the future.** As a nation, we fall short on this score when it comes to the elderly, the young and the poor.

Protecting vulnerable Americans of all ages is not a question of dollars alone. It is a question of public and political will.

Edward R. Roybal, Chairman
February 1986

NOTE: A formal hearing on the issue of intergenerational equity will be held by the House Select Committee on Aging in March, 1986. The Gerontological Society of America's final report on the common stake of generations will be released at this time. For more information on the hearing, please contact Nancy Smith or Austin Hogan at the House Select Committee on Aging, Room 712, Annex #1, Washington, D.C. 20515; Phone: (202) 226-3375.

INTRODUCTORY REMARKS

Fernando Torres-Gil, Ph.D.
Staff Director, House Select Committee on Aging

It is a pleasure to come before the distinguished membership of the American Public Health Association (APHA). I am Fernando Torres-Gil, Staff Director of the House Select Committee on Aging.

The purpose of tonight's forum is to call on the public, on health professionals and on the Congress to battle against the frightening trend that pits the elderly, the young and the poor against one another in the struggle for public dollars. The intention of our Committee is to establish that the needs of the aged and young are interlocked and require multi-generational solutions. It is also to dispel the notion of intergenerational conflict that threatens the very core of the family unit and jeopardizes what programs already exist for the elderly, their children and their grandchildren.

This session is particularly important with the Congress about to act on the Gramm-Rudman amendment to the deficit reduction bill. Our Committee analysis, which is being released tonight, shows that Gramm-Rudman could cut **from 27 to as much as 44 percent** from programs aiding America's elderly, children and poor (Appendix A). These cuts would come on top of five years worth of unwarranted cuts already incurred by essential health and social programs.

This session is also an important step toward linking the public health professionals, the public and policy-makers together in the protection of the public's health. In this spirit and in the shadow of Gramm-Rudman, Mr. Roybal has urged all of you through press releases and announcements to tell your Congressman to vote no on Gramm-Rudman. Your support is needed now more than ever to generate the political will we will need to protect needy Americans of all ages.

Congressman Edward Roybal, Chairman of the House Select Committee on Aging, had intended to preside over this forum tonight and to share the podium with Congressman George Miller, Chairman of the House Select Committee on Children, Youth and Families. Unfortunately, the pressures of their work in the last few days of the session do not permit them to attend. Their common interest in multi-generational issues is, nonetheless, a statement of shared concern for vulnerable Americans across the age-spectrum.

Tonight we will learn how the health problems of older Americans are a multi-generational concern and how they are being made worse by repeated budget cuts in essential health programs. This forum is only a first step. The Committee will continue over the months ahead to fight this notion of intergenerational conflict, and to fight for programs that protect all vulnerable citizens. We thank the panelists for appearing on behalf of the Committee, and look forward to their statements.

Before turning to our speakers, I want to draw attention to an important report being prepared by the Gerontological Society of America (GSA) that will be released early in 1986. This report will provide a solid argument against the notion of intergenerational conflict and will help to bring the issue of the common stake of old and young back into focus. We are releasing a synopsis of this report tonight (Appendix B). The Committee commends the GSA for sponsoring this report and looks forward to its release.

There are also many individuals deserving thanks from the Committee for their help in preparing for this forum -- more than I have time to mention. However, I do want to extend the Committee's appreciation to The Gerontological Health Section of APHA - the cosponsor of this event - and to Dr. Pearl German and Dr. Marcia Ory in particular for the time and assistance they generously provided the Committee. We also wish to thank Dr. Sidel, President of APHA, for the invitation to participate in this conference, and to his staff for their technical assistance.

At this time, I would like to call upon Dr. Sidel, the President of the APHA, and Dr. Pearl German, Chairwoman of the Gerontological Health Section, to comment on the importance of linking health professionals and policy-makers in the interest of improved health care for Americans across the age spectrum.

Victor Sidel, M.D.
President, American Public Health Association
Distinguished University Professor of Social Medicine
Montefiore Medical Center, New York

It is my privilege, as the President of the American Public Health Association (APHA), to thank your Committee, The House Select Committee on Aging, for holding this public forum in conjunction with the 113th Annual Meeting of the American Public Health Association. As your Committee is aware, this is the world's oldest and largest public health association. Through its members and those of its 51 affiliated state municipal pubic health associations, it represents some 50,000 health workers in the United States -- the highest number of members in APHA's history.

APHA has a long and continuing interest in the health and well-being of older people. Indeed, several people on the panel tonight will attest to the fact that the work done by public health professionals in APHA and elsewhere has been a major contributing factor to the increased life expectancy rate that has permitted so many of our citizens to reach what should be the peak, the very flower of their lives. And yet - even as the length of life has been extended by public health work - our society has not kept pace in finding ways to permit all of our older citizens to enjoy the fruits of their labor -- their reward for years of service to their family and community.

I wish to tell you one story that has some substance in relation to tonight's forum. As some of you know, Ruth Sidel, my wife, and I were privileged in 1971 to be members of the first U.S. medical delegation invited to the People's Republic of China since 1949. Dr. Paul Dudley White, the renowned cardiologist, and his wife were also members of that small delegation. The delegation was honored by an opportunity to meet with Dr. Guo Moro, then the President of the Chinese Academy of Sciences. Drs. White and Guo, both well into their eighth decades of life, discussed the ways in which aging is viewed in the two societies. The words of Robert Browning were quoted:

"Grow old along with me,
The best is yet to be,
The last of life for which the first was made."

There was discussion of the similar, and unfortunately, some of the very different ways in which the two societies view, protect, cherish, and honor their older people. What is fascinating is that a great part of that discussion was about the very theme that is our focus tonight -- the way in which younger people and older people in a society work together. Dr. Guo Moro explained how throughout most of China's history, there has been an attempt to foster ways in which young and old can work together to support their family and community.

We can learn a very great deal from the record of other societies. This is true not only in societies in Asia, but also in the industrialized democracies of Western Europe. We can learn the ways in which young and old can work together so that both can have what is necessary and deserved in their society. Young and old can work together to protect the health, the well-being, the resources, the self-reliance, and the dignity of all people, and together convey respect and honor for the attainments of older citizens.

Speaking for APHA, we congratulate our Gerontological Health Section and its Chairperson, Professor Pearl German, for cosponsoring this event. We also congratulate our Social Work Section and its Chairperson, Dr. Rosalie Kane, for the excellent work they are doing to bring about much needed changes in the way our society views its older people and responds to their needs. In my presentation to the Maternal and Child Health Section yesterday, I annunciated the theme that young and old must work together, and that I have never heard a stronger advocate for the rights of children than Maggie Kuhn, the Head of the Gray Panthers. What Maggie personifies is the fact that we are going to have to fight across the age spectrum for these resources.

In closing, APHA's Annual Meeting theme, "Government's Responsibility and the People's Health," makes it particularly appropriate that the sections represented at the table, and APHA itself, welcome you to our Annual Meeting, congratulate you on the work you are doing, and most importantly, pledge to work with you in this important effort. Welcome to the APHA.

Dr. Torres-Gil: Dr. Sidel, thank you very much for your insights and your hospitality. I would like to add to Dr. Sidel's comments that as the Committee and the Congress begin to address issues of intergenerational conflict, this organization will play an important role in providing a progressive and compassionate response to the needs of the young and the old.

Pearl German, Sc.D
Chairwoman, Gerontological Health Section
American Public Health Association
Associate Professor, Health Services & Development
Johns Hopkins University, Baltimore, Maryland

I wish to join Dr. Sidel in welcoming the House Select Committee on Aging. Our Section, the Gerontological Health Section, was founded within APHA to foster, develop, and guard the health and rights of older individuals and to insure the highest quality of life possible. The proceedings to take place here tonight speak to all of these objectives, and our Section welcomes this process.

The growth of our Section over the past seven years has been nothing short of phenomenal. This speaks to the concerns within APHA for older citizens. While every member of our Section works in one way or another for older persons, membership in the Section and in APHA overall expresses the belief that, as a group, we can achieve additional positive ends that are not possible through our individual actions.

It is our hope that the results of this public forum will combine with our Section's continuing efforts to further the cause of good health and good life for all older Americans. We applaud the action of the Committee and hope that this first - and it is a first - combined Congressional and APHA cooperative action will lead to future joint efforts between us.

Dr. Torres-Gil: Our first panelist tonight is a person who represents some of the tragic and real concerns of a good portion of the American public. She will share with us the emotional and financial effects that caring for two frail parents and a disabled husband has had on all members of her family.

For seven years, Mrs. Brushwood worked to meet her career goals and the financial needs of her family while also serving as the primary caretaker for her mother, a victim of Alzheimer's disease; her mother-in-law, a stroke victim; and her husband, also a victim of repeated strokes. Mrs. Brushwood will describe her family's experiences and suggest how the burden of care might be lessened for families in the future.

Anne Brushwood
Charlottesville, Virginia

In the last seven years I have made four moves; four job changes; lost my mother, but still had to take care of her; lost my husband - best friend and lover - but still have his care; been through one son's divorce, five grandchildren and one marriage, had my mother-in-law move in; and watched my mother die. All this, not to mention the loss of my career and social life.

I've been asked to speak to you tonight about being a caregiver and a decision-maker, and how it has affected our whole family. My story is not unique -- many people are going through even worse situations.

In 1978, my husband, Marshall, worked for a large pharmaceutical company. I was just beginning an exciting and lucrative career as a sales representative for a large computer company. Five of our six children were grown and beginning their families. Marshall's mother lived in her own apartment in Richmond, Virginia. My mother had been living with us since her retirement and helped with many household chores.

Then things fell apart.

Marshall, a diabetic, had a series of strokes and became disabled seven years ago. My mother was very upset over this and moved out of our home into an apartment. I hired a woman to come in to take care of Marshall while I worked. She wasn't an RN or LPN, so our insurance didn't pay anything, but she was so good, and I felt it was worth it. After several stays in rehabilitation centers and more strokes, it became obvious that Marshall was permanently disabled. I decided to move to Lynchburg to be closer to his doctor and the hospital.

In 1982, my mother was attacked by a purse snatcher and ended up in the hospital with three broken bones, completely disoriented and confused. The bones healed, but the doctors could not tell me what was wrong with her mind. I heard "hardening of the arteries" and "just getting old." I couldn't accept her getting <u>that</u> old in a 24 hour period, so we went through many tests and scans -- still no answers. It was to be six months before I read an article in the newspaper and went to my first Alzheimer's meeting.

I put Mother in a nursing home. It cost well over $1,500 per month. In order to visit her, I had to either stop traveling on the job or pay for an extra sitter for Marshall, as he was too sick to leave. He was in the hospital, near death, seven times that year. During this time, my son Scott came to live with me to help out. My two sisters came from Atlanta and Dallas to spend their vacations helping me.

Mother had her social security and some savings. We figured that would be gone within one year. Visiting her and taking care of Marshall, plus trying to travel, was taking its toll on me emotionally and physically, not to mention financially, so I decided to bring Mother to my house and let her help pay for the nurse and preserve her savings for later on.

That worked out for nearly a year, until my nurse had a heart attack. I tried several agencies. Since Marshall needed shots, they would only send an LPN or RN at $12.00 per hour. They would not do housework, consequently I came home exhausted and had to do laundry, shopping, cooking and housework. I tried live-in help which was a disaster and various other people -- none satisfactory.

At this point, I began having black-out spells on the road. My doctor said I was going to have to give up something. I quit my sales job and moved the family back home to Charlottesville to be closer to friends and children, and took a less demanding job. The move made my mother worse. A lot of our old friends came -- but only once. It quickly became apparent that any social life was out. Our children came, but it was uncomfortable for them -- Marshall wouldn't talk and Mother didn't know who they were. Scott got married and he and his wife helped out financially and with caregiving.

A month after we moved, Marshall's mother, who had had a stroke and various other physical ills, became very depressed. Her doctor said she was unable to live alone. Nursing homes were again looked into, but there was "no room at the inn" -- long waiting lists. I figured one more wouldn't make any difference, so my mother-in-law moved in. I found a male helper who had been an orderly. He learned to give shots, did housework, and was wonderful with everyone.

By this time, there were six of us living under one roof, and three dependent on me as their primary caregiver.

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The house we were renting was sold and I had six weeks to find a house, get a loan and move. I found that most houses in our price range (and out of it) were not designed for handicapped people, but I finally found one.

My mother became much worse and stopped sleeping at night. My male helper left and we again went through a series of aides and nurses. This was very hard on all of us. The association I worked for was moving to Richmond, so I knew I had another job change to deal with. By this time I had about had it. I was averaging two to four hours of interrupted sleep a night, Mother and Marshall were both incontinent, I broke out in a rash -- cried a lot, and the black-out spells came back. I was sure I was getting Alzheimer's.

My doctor was urging me to put Mother in a nursing home. I felt this would be impossible for me emotionally and physically, to be in three places at once. It would also be hard financially because I would still have to have a nurse at home. My salary was only a little more than I was paying for help. I asked for a Medicaid evaluation for Mother. She was approved for nursing home care, or eight hours a week home care, which I would have to pay for, and that nurse would only help her.

There seemed to be no choice but to quit my job, so I decided to stay at home and become a full-time caregiver. That was just this past July.

At 2:30 a.m. of what was to be my first day at home, Mother fell down the stairs. The Emergency Room doctor wheeled her out - face swollen and full of stitches, blood from head to toe and nearly unconscious - and told me I could take her home. I nearly fainted. He said Medicare wouldn't approve her being admitted and he tried to explain the DRG system. I told him what I thought of the "system". We finally got my doctor on the phone and he agreed to admit her because it would be easier to get her in a nursing home from the hospital.

I remember hearing that Mother could live for several more years, then several more months, but I felt I was watching her die. She died three and one half weeks later. One of the hardest decisions we made was not to use life support.

As you can see, the responsiblities of long-term care can be devastating, emotionally, physically and financially -- regardless of whether it is at home or in a nursing home. I still have a long way to go. Sometimes I feel it might be easier to just pack them off to a nursing home -- but that would mean giving up. It wouldn't be long before everything we have would be gone. Then, who is going to take care of me? Because of the stress of caregiving, I am no longer able to be a productive person who can work and pay taxes.

And the pressures of caregiving have touched the other members of my family. My son and daughter-in-law live with this on a day-to-day basis. They have had mother crawl in bed with them in the middle of the night. They have been routed out of bed to go to the hospital for emergencies. They have a very limited social life. It is hard for them to have friends over, although when their friends do come, they are very understanding of our situation and bring youth and laughter to the house. They pitch in their money, their time, their energy and I don't know what I'd do without them.

It makes me sad that they spend so much of their lives, and their entire married life, surrounded by illness and sadness. Wouldn't they be better off living on their own and having a more normal life? My son and his wife have attempted to put their own feelings and fears into words for the Committee. I would like to add their thoughts to my statement.

It's a sad situation that there are many people like me who want to make their own way and to keep their loved ones at home. It goes against my grain to think of my family on Medicaid or welfare. Just a little help would make a big difference for the entire family. Right now there is no insurance that will help out with long-term care, but you can give up everything and the

government will take over and spend a lot more money on a poorer quality of care. And the toll on the family - young and old alike - is enormous. It seems to me it would make more sense to take about a third of that money to help keep people at home and use the rest for much needed research and helping more families that are unable to give home care.

People say, "How do you do it?"

You do it by living one day at a time (only so much can happen in 24 hours). A strong faith in God. A supportive family. Keeping a sense of humor. Becoming involved in support groups and trying to help others who are going through this.

My story is not unique. It is repeated in thousands of households across the country. I know I am not alone, although sometimes I feel that I am.

Dr. Torres-Gil: Mrs. Brushwood, on behalf of Chairman Roybal and the Committee, we not only want to thank you for sharing your remarks, but for sharing your own personal anguish and the personal problems you have faced. Your thoughts will be shared with other members of the Committee so that they can better understand what the real human problems and needs are.

Prepared Statement Submitted by Mrs. Brushwood's Daughter-In-Law, Brenda Nichols

When I first met the Brushwoods, Marshall was very sick, and in and out of the hospital a lot. Anne was trying to travel and always seemed to have work to do at home, plus the normal household chores. Grandma (Anne's mother) lived in an apartment in a nearby town and, though forgetful about some things, enjoyed traveling, hiking in the mountains, and made beautiful crafts.

When Grandma was mugged, she came to live with Anne, and this is when our lives began to intertwine. A lot of the time, Grandma seemed like a normal elderly person, yet we were pretty sure she had Alzheimer's, and we had to help her more and more with the activities of daily life.

One of the big problems at that time was whether to tell her she had Alzheimer's when she would get upset and say she was going "crazy". We never knew how she was going to act. In order to deal with what was happening, Scott and I would joke about it around our friends, and at times this made us feel guilty for laughing, yet it helped us deal with the situation. Sometimes it seemed that all we ever had to talk about with our friends was Grandma and the things she was doing.

Grandma got very upset and confused on our wedding day. I had been up with her several times during the night, and that morning she didn't know who I was and was afraid of me. Anne was crying and I was crying and wishing that we had gone to the justice of the peace.

When we moved to Charlottesville, I was promoted to manager and was very busy with my job and had to work long hours. Marshall's mother came to live with us. Many nights Grandma would come into our room and touch us when we were sleeping, or crawl in bed with us. We would take her back to bed, trying to be quiet so Anne could get some rest.

Scott and I talked about how tired Anne looked all the time and how she didn't get out of the house enough. Our friends were very understanding and came around, yet her friends came less and Grandma's friends never came at all.

Scott and I tried any way we could to help out. I gave Grandma baths, dressed her and put her down at nights. She frequently had a look in her eyes of "Who are you?", "I am confused", that would bring tears to my eyes. Anne taught me how to give Marshall his shots and

test his blood, and I got so I could even help him with the urinal. It was a real family effort to take all three of them for an outing. Scott helped around the house, with meals, and has certainly done his share of "sitting", along with working 10-hour days.

The night Grandma fell down the steps we all had our guilt feelings about why we didn't hear her get up like we had so many times before. At the hospital, Scott broke down in tears and kept saying, "Hasn't she been through enough?" Anne nearly went into shock -- we were afraid for her, and so thankful that we were home to be with her.

The night Grandma died was a relief -- she had suffered so much, and we were glad she was finally at rest.

Scott and I can't help but worry about the future. Now that we know for sure that Grandma had Alzheimer's, we are wondering what causes it; is it inherited? If it is inherited, will Anne, Scott or Alicia (Scott's daughter) get it? I have been going to the Alzheimer's support group meetings to learn as much as I can about this horrible disease. More research is desperately needed. We are just about depleted financially and emotionally now. Can we go through two more generations of Alzheimer's?

It seems so unfair in Grandma's case -- she worked all her life so she could retire in comfort and enjoy her later years, and leave something for her children. Alzheimer's took it all away. Marshall needs a lot of care and can't be left along for very long, but he is only in his 50's -- too young for a nursing home. Even though he doesn't talk very much, you can tell he enjoys being part of the family. His mother has really been happy here in the family and appreciates everything we do for her. It is hard at times, but not nearly as hard as abandoning them to an institution would be for all of us.

We don't know what the future holds for us. But whatever it is, we will try to work it out together.

Dr. Torres-Gil: Our next panelist is Dr. Rosalie Kane. Dr. Kane is a professor in the School of Public Health and the School of Social Work at the University of Minnesota. She was formerly with the Rand Corporation and with the University of California at Los Angeles. Dr. Kane has worked as a practitioner, professor and researcher in aging, and is particularly well known for her work in long term care policy.

Tonight Dr. Kane will present evidence for the interdependency of the aged and their family members; the toll that caring for a dependent elder takes on the entire family; the impact of current medicare and Medicaid policies on the aged and their families; and priorities for reform.

Rosalie A. Kane, D.S.W.
Professor, School of Public Health
& School of Social Work
University of Minnesota

I wish to thank the House Select Committee on Aging and Congressman Roybal for holding this important forum tonight. I don't think anybody could have listened to Mrs. Brushwood and be left with any other impression but that the care of the elderly and disabled is something that affects people of all ages.

I am Rosalie Kane, a professor at the School of Social Work and the School of Public Health at the University of Minnesota. Much of my career has been devoted to studying and trying to improve the circumstances of health care and long-term care for the elderly. I can say with assurance that few issues more vitally affect Americans of all ages than the kind of care the elderly receive and how it is financed.

I will begin with a quotation:

> "It must not be forgotten that the core of any social plan must be the child. Old age pensions are in a real sense measures in behalf of children. They shift retroactive burdens to shoulders that can bear them with less human cost, and young parents, thus released, can put at the disposal of new members of society those family resources he must be permitted to enjoy if he is to become a strong person, unburdensome to the state. Health measures that protect his family from sickness and remove the apprehension of debt are child welfare measures. Likewise unemployment insurance is a measure on behalf of children because it protects the home. ...public job assurance which can hold the family together over repeated periods of private unemployment is a measure for children in that it assures them a childhood rather than the premature strains of the would-be child bread earner."

These are the words of the Report of the Committee on Economic Security and the date is 1935. Fifty years ago the framers of our Social Security Act knew that the age generations are interdependent. Fifty years ago they understood that societally guaranteed benefits to the elderly benefit children and young adults because those public dollars relieve younger generations of heavy financial burdens.

Somewhere in the last 50 years we have lost our understanding that age groups are interdependent. Instead, the popular press and some political rhetoric have highlighted a supposed imbalance between public dollars spent on the young and public dollars spent on the elderly. Such commentators foresee a bitter intergenerational conflict just over the horizon. But this concept of intergenerational conflict is vastly oversimplified. It ignores the reality that people of all ages are tied together in families and have a stake in each other's well-being. It is at best distracting and at worst dangerous.

Intergenerational conflict is a distracting idea because it diverts attention from the real issue: How can families (and even people without families) be protected adequately from financial disasters which, when they strike, can devastate a family unit financially, socially, and emotionally? How can people with disabilities and diseases that create serious dysfunction receive care in a way that enhances their independence and dignity?

A narrow focus on balancing resources spent on the social welfare of those now young and those now old is an unhelpful approach to social policy. The new report by the Gerontological Society of America eloquently argues that we must look at fairness across the life cycle, considering that those now old were once young and those now young hope to become old, and the generations are cemented by bonds of duty, affection, and interdependence. Furthermore, we must reject the tacit assumption that existing social welfare dollars should compete. Other expenditures can be examined, and sources of new revenue can be considered. Surely a country as wealthy as the United States can protect all its citizens at least as well as many poorer countries do.

The idea of intergenerational conflict is dangerous too. At present, no such conflict exists as a systematic phenomenon. On the contrary, when younger adults age 18-64 are asked to indicate which public programs they would support, even if an increase in taxes were required, they overwhelmingly favor income security and health care for the old. And elderly persons continue to support public programs that protect and educate children, and that preserve the community and the environment for future generations.

In the context of private family life, as Mrs. Brushwood pointed out, younger generations make enormous sacrifices of time, energy, opportunity, and money to care for the elderly. Similarly, older people care vitally about the well-being and security of their offspring, often making life choices they themselves

dread in order to avoid being a worry or a financial drain to their family. Seniors deprive themselves to protect even small legacies for their heirs. The interests of the young, the old, and the in-between are inextricably linked. Let's not ferment a conflict by constant speculation about its possibility.

The intergenerational conflict idea has an insidious corollary--the idea that the elderly receive more than their fair share. The relative reduction of poverty among the elderly--the triumph of Social Security--is usually described in the same breath as increasing poverty among mothers and children. This formulation ignores the great variability of income among those over 65 and the poverty of the very old, especially women. Ludicrously, it also seems to suggest that we can attack lack of opportunity among youth and the conditions that generate extreme poverty by reducing the average income of the elderly.

We constantly hear and read statistics that persons over 65 use health resources out of proportion to their numbers in the population. The tone invites us to deplore that 11% of the population over 65 use more than 40% of hospital days. But surely the elderly need a disproportionate share of health care just as children need a disproportionate share of educational services. If the elderly only used 11% of hospital days something would be greatly amiss. The real question is the more basic one of effectiveness. Is our large expenditure on health care of the elderly doing all the good we have a right to expect? Are hospitals and long-term care programs serving the elderly well? Or do our practices hurt the elderly and, therefore, family members of all ages?

In fact, the hospital does not always serve the elderly patient well—this is particularly true for the very old person over age eighty, especially once the acute phase of disease has ebbed. Hospitals with their associated bed rest, confusion, and depersonalization can be dangerous for old people. Precipitous decisions about

where they go after leaving the hospital can drastically reshape their lives. The DRG form of prospective payment exacerbates the problem for an elderly person with multiple diagnoses and the need for a careful medical assessment of the whole picture. The hospital has every incentive to pare down length of stay, minimize the service given, refrain from comprehensive assessment, and promote hastily contrived aftercare plans. Relatives of the patients, sometimes themselves elderly, sometimes from out-of-town and unaware of resources, are typically informed that they must get the patient out of the hospital immediately.

What happens after the hospital is usually some form of long-term care. Long-term care at any age is difficult to arrange and finance. The elderly are the group most needing long-term care, but let us remember that other groups are affected as well. Chronically and seriously ill adults, such as paraplegics or persons with advanced multiple sclerosis, adolescents or young adults who have been brain-injured in accidents, and developmentally disabled children who can expect a decade of long-term care, can testify to the problems and the costs. Caregivers come in all ages and relationships and sometimes the elderly themselves care for a younger relative. Indeed, the cost of long-term care for a physically or developmentally disabled child vastly exceeds the average cost for an elderly person.

From the viewpoint of the consumer, the long-term care experience of Mrs. Brushwood is repeated over and over again. Practical services for people living in the community are hard to find and even harder to afford. They are elusive, unreliable, and of uncertain quality, whether they are financed by public dollars or the users themselves. Family members - spouses of the elderly and the disabled younger adult, children of the elderly, parents of disabled children and young adults - are the providers of the vast bulk of long-term care, but they get little organized help. All age groups have a common stake in the development of effective, reliable, and efficient noninstitutional long-term care services.

Next to hospitals, nursing homes are the largest public investment in services to the elderly, and too often they exact an intolerable price (in dollars and misery) from their users. Suffice to say that one out of four who survive to 65 will enter a nursing home; that almost all who retain cognitive abilities will be terrified and desolate beforehand; and that too many will be bored and demoralized afterward. It is unconscionable that our public policy is built on an institution that, as presently organized, is so unacceptable to the user. All age groups have a stake in improving the quality of life in nursing homes. That nursing homes also impoverish the residents, reducing them to the status of paupers, is the last straw.

Nursing home costs are fast approaching 30 billion a year. Half of that is paid by governments through the Medicaid program but the other half was paid through private funds. These users were required to spend down to Medicaid levels and deplete the legacies they had prepared for their children before receiving Medicaid help. Those who disposed of assets before entering a facility lost the dignity and control that came with those possessions. And, the elderly nursing home resident has usually already expended large sums of money on home care before beginning the nursing home spend down. When the resident is married, the spouse will also be forced into poverty as their joint assets are spent down.

There is a sharp dichotomy between the nursing home and all other services. Efforts to find alternatives to admission have accentuated the notion that those in facilities are therapeutic failures. It is left to the nursing home to provide full services (housing, food, laundry, housekeeping, personal care, nursing, entertainment, stimulation, rehabilitation, transportation, and spiritual fulfillment). Nursing home residents tend to be ineligible for any other publicly funded services that are offered the disabled — for example, transportation, congregate meals, community colleges, etc. In fact, if community services are brought to people in facilities or if funds are used to bring the nursing home resident to the service or program, this is usually considered an inappropriate co-mingling of federal funds.

The status quo is untenable and demoralizing for people of all ages. I and everyone else I know in geriatrics receive constant telephone calls from frantic family members asking what can be done for their mothers or fathers. So far all we can do is make referrals for those lucky enough to live in an area with well-developed programs and commiserate with the others. What would be more ideal? Here are some outcomes I would wish for elderly people in general:

- **An adequate income.** The basic income must not be undermined by large, unpredictable health-related expenses such as nursing home care, which can easily consume more than $30,000 a year.

- **Meaningful roles and activities.** The way we provide care to the elderly should not preclude their participation in community programs with people of all ages. They should be able to use their skills and experience on behalf of the community and, indeed, younger people should not be deprived of contact with the elderly.

- **Optimal functioning with as much independence as possible.** This means each older person must have the benefit of adequate diagnosis and treatment of functional problems. Eye, hearing, and foot problems must be worked up; prostheses and dentures must be available as appropriate. Treatable problems causing confusion, incontinence, or other disability must be identified and aggressively treated. Drug regimens must be skillfully planned and monitored. Nothing is more wasteful and inhumane than organizing care (much of it provided by family members at that) for problems that could have been corrected in the first place.

- **Reasonable contentment.** This is not a naive prescription for happiness which cannot be guaranteed at any age. Some depression and anxiety is synonymous with life itself. However, the rampant depression among the elderly at present is an unacceptable outcome.

- **Ability to remain involved members of the families.** Older people should be able to participate in the reciprocal exchanges of support and attention that are the hallmark of family life. Although this is uncontroversial - everyone is pro-family - the implications are debatable. For older persons to be best integrated into family and community life, I maintain that their children or other relatives should not be seen as the basic source of their income, services or care. Such policies do not enhance living family relationships and a policy that makes the family the unit for conferring benefits is inequitable. If people without children or a spouse are given services relatives would be expected to provide, the policy unfairly penalizes those with families. But if government offers few services because the family is expected to bear the brunt, it obviously penalizes those without families.

- **For older persons with severe cognitive impairment, maintenance in as comfortable, pleasurable, and anxiety free state as consistent with their condition.** Relatives of the severely demented deserve confidence that their demented relative can eventually receive such care outside the family. I see no overriding value in a social policy that expects one usually older person to exhaust and expend himself caring for another who no longer knows where or who he is because the alternatives seem too grim.

- **Ability to make choices.** Unless cognitively impaired, older people should be free to make their own life decisions. This means access to information needed for informed choices and mitigation of the crisis atmosphere that now accompanies the health decisions of the elderly.

To achieve these goals, it may not always be best for the older persons to live in a private home. On the contrary, some sort of collective housing might sometimes afford more dignity and independence.

Public policy for health and social services must be predicated on these axioms: all age groups are interdependent; the young have a stake in the policies for the old and the old have a stake in the policies for youth; families by and large prefer to give and receive help within the family unit; an enormous amount of help flows from old to young and from young to old; contrary to myth, the elderly have not been deserted by their families; and the need for long-term care severely stresses any family who encounters it. If these are the salient facts, what are the policy implications?

Ideally, most policies should be age blind. The exceptions are policies that govern retirement and income security, and this is already recognized in our Social Security policies. Retirement policies serve two functions, they allow people in taxing or strenuous occupations to reach a desired end point and they allow younger persons orderly access to opportunities in the work-place. As long as the right to retire is determined by age as well as, of course, by disability for those of all ages, income maintenance must follow the same categories. The age of mandatory retirement could surely be reconsidered (as long as those with disabilities are not forced to work because of inaccurate eligibility processes). Also it is perfectly equitable for Social Security to count as income for tax purposes.

Ideally, health and long-term care policies need no age criteria to determine eligibility to publicly supported assistance. Serious illness and the consequent need for assistance to compensate for functional impairment is, of course, more likely among the old (who also have less income to withstand the problem and who, especially at advanced ages, are likely to be widowed), but people of all ages are subject to catastrophic health and long term care costs. A national health insurance scheme would provide equal protection to all.

In our current cost-cutting, deficit conscious phase, national health insurance seems like an unaffordable expenditure. However, in a country where medical and hospital care is organized much like here - that is in Canada - the national insurance for hospital and

medical care has managed to contain health care costs. The Canadian provinces even insure long-term care. This means that any person--regardless of age or income -- is eligible for long-term care at home or in a nursing home if he or she is judged to need it for functional reasons. Health care is free at the point of use but charges are made for institutional long-term care. Such charges are justified because all citizens need to pay something for housing and food. Yet these charges are identical for poor and rich (though the latter are free to purchase other amenities) and are affordable by the poorest pensioner.

Taking all health care costs together, Canadian health care costs less per capita and less as a percentage of the GNP than does care in the United States. The main reason that Canadian health care, even with its inclusion of long-term care, is less expensive than the U.S. counterpart seems to be the increased control that the provincial governments have in their position as sole payer. This means that the government can get a handle on both quality and price.

And the national health insurance programs are immensely popular. A well-to-do Canadian television executive told me that his parents were ill and in and out of hospitals and other care during the last decade of their lives. Each time he saw their huge hospital bills with the bottom line "Paid in full by the British Columbia Health Insurance Plan," he told me that he realized he would gladly pay his taxes forever. Yes, he could have afforded to pay for the hospital care (something most people could not manage) but he then would have been less able to make frequent cross-country visits to his parents.

National health insurance should be reinstated as a goal, but meanwhile, let us concentrate on immediate policies regarding Medicare and Medicaid.

First, Medicare coverage needs modification in several respects. Geriatric assessments on either an inpatient or outpatient basis must be covered. Such assessment is needed to identify those remediable problems that account for unnecessary impairment. It is an astounding fact, for example, that most of the people labeled as incontinent or demented have not even been medically worked up for the problem. Yet, dementia and incontinence - which require so much - are not in themselves diseases but symptoms. And changing the language to Alzheimer's disease (which is a specific syndrome thought to account for about 60% of senile dementia) does not help unless the label is conferred after a proper work-up.

Coverage is also needed for dental, optometry and podiatry services; for drugs, eyeglasses and hearing aids -- in short, those items that bear direct relationship to improving functioning and minimizing the care needs. Higher copayments and deductibles are <u>not</u> a good way to go, especially since the elderly are more out-of-pocket for health care than they were before Medicare was established to protect them from catastrophic health expenses.

Second, a chronic care (or long-term care benefit) is needed under Medicare. Present limitations on nursing home care to skilled services for the rehabilitatable and limits on home health to skilled services for the homebound rehabilitatable place enormous strain on the elderly and their families.

In those places where we have tested out what happens when more generous benefits are offered the elderly, we have found that their family members do <u>not</u> disappear. They remain affectionate and involved, and they still continue to provide help with homemaking, transportation, and other chores. Consumer demands on a long-term care benefit turn out to be reasonable. Granted, a good home health service that emphasizes personal care relieves family members of tasks such as bathing or diapering a parent, but surely these are rather inappropriate tasks for family to perform.

Third, waivers should continue to be granted to allow innovations such as the Social Health Maintenance Organization that examine new ways of conceptualizing health care and long-term care and sharing the financial risks.

Fourth, and particularly in the absence of an adequate chronic or long-term care benefit under Medicare, Medicaid waivers should continue to be permitted for community based long-term care programs and case management services to allocate resources. It is essential that the eligible populations go well beyond those categorically eligible for Medicaid, because so many of the vulnerable population reach Medicaid eligibility within a year of entering a nursing home. In fact, we might consider changing the basic Medicaid program to mandate that persons who are functionally eligible for nursing home care and who would be eligible for Medicaid within 180 days of nursing home admission receive homemaking and personal care services under Medicaid as authorized by a case manager.

Fifth, for the sake of everyone using long-term care programs and all their family members, we must have the political will to deal with the quality problems in institutions. This is purely and simply a governmental responsibility. At the same time, we must begin to examine how to ensure quality of care in home-based programs where monitoring may be even more difficult.

Sixth, we should experiment with new forms of housing that might permit nursing and home care services to be delivered to many of the frail elderly where they live. The advantage would be that the cost of housing and hotel-like services could be separated from the costs of care. Long-term care users could continue to pay their housing costs from undepleted incomes while the care costs could be purchased in a variety of other ways and, I hope, borne by Medicare and/or Medicaid. This would save many people from suffering in a restrictive, hospital-like environment as a condition of long-term care.

Nobody will be more eager for these reforms than the family members of the frail elderly who currently are stretched thin in their efforts to meet multiple needs of all dependent family members while generating an income as well. Each family seems to encounter the horror of long-term care alone. Alone, they discover that there are not enough hours in the day or dollars in the bank to meet needs. Alone, they discover that they cannot buy the services that their parents or spouse need - that they only come in a highly professionalized flavor or not at all - and alone they are shocked at the necessity of seeing their relatives enter nursing homes, many of which are substandard.

So far, the cries of disapproval and outrage have been muted - perhaps because so much energy is drained by each family's individual odyssey against the forces of long-term care - but the general public is ready to act for the collective good in improving health and long-term care and is eager for the political leadership that will start the ball rolling.

Dr. Torres-Gil: Thank you very much Dr. Kane. The Committee thanks you for your excellent presentation. We commend your research in this area and, speaking for Mr. Roybal, we certainly support your recommendations.

Our last panelist is Mr. Jacob Clayman, Chairman of the Leadership Council on Aging Organizations and President of the National Council of Senior Citizens. Mr. Clayman will describe how the health and financial needs of Americans across the age spectrum are interlocked and how budget cuts over the past five years, and, now, under the proposed Gramm-Rudman Amendment, jeopardize essential health programs for the young, the old and the poor. Mr. Clayman speaks on behalf of the Leadership Council of Aging Organizations -- a coalition of over 50 national aging groups serving the elderly. It is a pleasure to have you here tonight.

Jacob Clayman
Chairman, Leadership Council of Aging Organizations
President, National Council of Senior Citizens
Washington, D.C.

Thank you Mr. Chairman and friends. Just as I was about to leave my office to come here tonight, I received word that Congressman Roybal and Congressman Miller could not come, and for good reasons. It may be just as well because in their absence, we may feel more free to talk informally to each other. Chairman Roybal would have been impressed by what was said here so far this evening, but he is already convinced. Mr. Roybal is not our problem. When I say our, I am assuming that your organization, the APHA, represents the right side of the issues that we are talking about.

But you, the APHA membership, are important. You make, in essence, the decision to send Mr. Roybal or somebody on the other side of the fence to Washington, D.C. You obviously are people of influence in your communities. You are the kind of people who will determine what type of Congress we will have come next session. That is as important as anything any of us can do.

I had the advantage of reading Mrs. Brushwood's statement in advance. Because she's so calm about her problem and was so extraordinarily controlled as she spoke to us tonight, I got more of a sense of the strength of the woman and the tragedy that befell her and others like her from reading the statement. I said to myself, "that statement would bring tears to the unseeing eyes of a wooden mannequin!"

I'm a tough old bird. I've been around a long time and I'm not easily moved, but while reading that statement, I felt emotions charging through me because it is so beastly true — because these are the facts of life for millions of Americans never seen and sometimes never known.

We, as a society, have permitted Mrs. Brushwood to assume this total responsibility - this awesome responsibility - without serious help from elsewhere. But we don't dare be taken in by her comments. She tells us that there is an intergenerational flow -- babies, youngsters, teenagers, middle-aged, and aged, that affects one member of the family or perhaps every member of a normal family.

Now, let me tell the painful story of how this Administration and many in Congress are thinking about vesting even more pain and anguish on people like Mrs. Brushwood and millions of others in our society by cutting social benefits in the next decade. Much of the talk in the White House is about drastically slashing the social programs which preserve the life, health, security and hopes of the young and the old.

Let's take Gramm-Rudman. This is a political statement pure and simple. Let me list some the programs which will be adversely affected: food stamps, Medicare, Medicaid, SSI, student aid, Aid to Families with Dependent Children, grants for preventative health, maternal and child health, grants for special food programs for low-income pregnant women, rehabilitation services for the handicapped, special programs such as senior centers, food centers home delivered meals -- all of these and more.

It appalls me that Gramm-Rudman would cut 38 billion dollars just from Medicare and Medicaid from now to 1990 -- 38 billion dollars. That is a fantastic sum even in this world. The fact that some programs would be cut as much as 25% by 1990 and that all effective programs would be pruned to the tune of 304 billion by the same year is a shocking prospect.

All of the programs I've talked about and those I haven't mentioned would be cut 304 billion dollars if Gramm-Rudman goes into effect. What does that do to children? What does that do to pregnant women? What does that do to their education and nourishment? What

does it do to young adults wanting to go to college but who can't afford to when our system has made it possible for others to go? What does that do to the programs that you lay your hands on everyday in your work?

This would be the greatest blood letting in the history of social progress in America. We can't imagine the devastation that this would heap upon the people of society. Cuts upon cuts have been vested upon the young, the old and the poor over the past five years. I was stunned to realize that over the past five years, programmatic cuts have totalled more than 300 billion dollars, affecting such programs as Medicare, Medicaid, food stamps, and housing.

So I say to you as I would have said to Chairman Roybal, we must stop this Gramm-Rudman monstrosity before it distorts most of the humane and rational social policies that have been part of our country and made us a worthy example to the world. We need a philosophy in the White House and the Congress that recognizes that the first duty of a sound and wholesome government is to enhance the human condition of our people - all our people - the poor, the middle class, the rich, the young, the middle aged, and the old.

This is what the Leadership Council of Aging Organizations advocates this evening.

Prepared Statement Submitted by Mr. Clayman

I am Jacob Clayman, Chairman of the Leadership Council of Aging Organizations (LCAO). The LCAO is a coalition of 30 national groups which represent or serve the nation's elderly population. LCAO members know well the impacts which elderly individuals' health and functional status have on their families. Mrs. Brushwood's story, tragic and alarming in its extent is, unfortunately, one which many families throughout the country can also tell.

It is critical that the interrelationship among the elderly's health, the family, and federal policy be brought to public attention. The Leadership Council of Aging Organizations applauds Chairman Roybal, members of the House Select Committee on Aging, the American Public Health Association President Sidel, and the Gerontological Health Section Chairwoman, Dr. German, for taking that step through tonight's forum.

The LCAO urgently calls upon the members of Congress, health professionals and the public to recognize two vital components of support for the aged: the intergenerational support which the federal government provides to families through its policy toward the aged; and the role which the family plays in the health and well-being of the nation's aged.

Programs such as Social Security, Supplemental Security Income, Medicare, Medicaid and Food Stamps are well-known sources of income and health security for the over-65 population. Equally important are the benefits which these programs provide to the families of the aged recipients. For example, Medicare, as the federal health insurance program for the elderly and disabled, helps to insure families against financial catastrophe if an older member requires hospitalization. Social Security enables millions of senior citizens to escape poverty and lead relatively independent lives.

Federal programs address very specific requirements and fall far short of meeting the aged's chronic health and long-term care needs. The adequacy of programs to fulfill their purpose directly affects the burdens the family must bear in filling the gaps. Studies show that the majority of long-term care is provided by the family. The source of 90 percent of current financing for long-term is personal income of the individual in need of care or the family. It is not surprising to note that Medicare's expenditures for nursing home and home care account for less than four percent of the program's outlays.

As the population ages, few families will not be called upon to physically or financially (or both) help an older relative. It is estimated that one-half of all middle-aged couples have at least one elderly parent. Most of the informal providers of care to today's dependent elders are in late middle age or in old age. They are family members who have their own younger dependents to provide for, are currently working, or who themselves are coping with advancing age.

As families like that of Mrs Brushwood or those who have testified before this and many other Congressional committees so graphically state, families want to help their aged relatives. However, they tell us that helping brings problems of financial hardship, emotional stress, and physical strain to the family. The effects of these problems can be major sources of intergenerational strife. Such strife, often avoidable, and its attendant misunderstanding can be greatly reduced by sensitive and sensible public policy. Unfortunately, it can also be exacerbated by shortsighted public policy.

It was sensitive and sensible public policy which led to the enactment of social policy milestones such as Social Security and Medicare so vital to today's elderly and their families. However, the departure from such sensitive and sensible public policy will lead to the breakdown of federal support for the family provided through aging policy. We have seen signs of this breakdown from budget cutbacks in recent years. We fear a further and irreversible deterioration of this intergenerational support if proposals such as the across-the-board deficit reduction plan called for by Senators Gramm, Rudman and Hollings are adopted.

On behalf of the Leadership Council of Aging Organizations, I would like to express deep concern over the Gramm-Rudman-Hollings Balanced Budget and Emergency Deficit Control Act of 1985. This ill-conceived legislation, hastily fashioned without public hearings or input, will not just commit the country to a rigid fiscal policy. It will also bring about consequences which are impossible to measure or anticipate, but which

are expected to have far-reaching effects for many years on millions of Americans. Yet, Congress is being asked to accept this "pig in a poke" plan. It is a plan about which Senator Dole exhorted Congress to act quickly before members had a chance to study it and realize how devastating it would be.

We know enough about the plan to recognize that it would make the health budget cuts of the last four years look superficial. If Gramm-Rudman-Hollings becomes law, as the Senate recommended, health funding for the aged, poor, and young Americans by 1990 will be reduced by 25 percent from current law. To reach deficit targets by 1990, Congress would have to cut Medicare and Medicaid alone by $38 billion. These cuts would come at a time when old and young alike are struggling with increasing gaps in funding for health and welfare programs.

Every conceivable program which helps the elderly or helps families assist in their responsibilities toward their own children or their aged relatives would be cut. Why would Congress, by adopting the legislation, ask families to make choices between nutrition to benefit pregnant women and their unborn babies, or preventive health measures for young children, or education for college age youngsters, or care of disabled adults, or maintenance of older people in the community? Why would the American people accept or force these choices on their fellow citizens? Why would they ask Congress to adopt legislation that strikes so harshly at the elderly and poor?

We believe that if they took a closer look at Gramm-Rudman-Hollings, Congress and the public would reject the proposal. A closer look at the plan would reveal that by 1990, it would force SSI recipients to live on incomes five years behind inflation, while today an individual recipient's SSI income is only 76 percent of poverty. A closer look would reveal that the nutrition assistance to the aged through senior centers and home-delivered meals, as well as Food Stamps, would be cut. A closer look would reveal that low-income families with

young children could lose income, health insurance, special nutritional assistance, and education opportunities. A closer look would reveal the devastating impact that Gramm-Rudman-Hollings would have on old and young alike.

Whatever version of the legislation is adopted, severe cuts in health programs will be made. The LCAO recommends that steps be taken to alleviate the burden which low-income individuals and families with elderly members would have to shoulder as a result. These steps, for example, would exempt low-income programs from deficit reduction and place Medicare and Medicaid in Category I, sparing beneficiaries and their families as much hardship as possible.

The Leadership Council of Aging Organizations recognizes the growing burden which the Federal deficit places on the nation and its lawmakers. We ask you, as responsible public policy-makers, to reduce the deficit and protect the nation's health. Both goals are achievable.

Dr. Torres-Gil: Thank you, Mr. Clayman, for your warning and also for the emphasis on the need to understand and respond to Gramm-Rudman. Mr. Clayman is involved in that battle on a daily basis so he certainly knows of what he speaks. We have a little bit of time so we will be allowing questions from the floor. Before we do, I'd like to begin this process by asking each of our panelists a question on behalf of Mr.Roybal.

Dr. Torres-Gil: Mrs. Brushwood, do you fear that the cost and burden of caring for your family at home may force you to place one or more of them in a nursing home before you want or need to?

Mrs. Brushwood: The burden, yes. As I said in my statement, sometimes I feel that to preserve my own well-being it would be easier to put them in a home. The fact is, I can't afford nursing home care right now.

Dr. Torres-Gil: Dr. Kane, based on your research of national health insurance systems of Canada and other countries, would you agree that the concept of an American health plan that protects citizens of all ages and needs is a viable one and practical for this country?

Dr. Kane: Yes, I certainly do think its a viable concept. It's probably an essential concept. The fragmentation that we now have with Medicare and Medicaid stands in the way of an efficient reorganization. The real question is, "can we afford a viable plan that protects all people?" I would respond that there are ways of controlling costs.

One way is through case management and another is through targeting of services. The most important thing in answer to your question is that when you think about the costs of care, it is very important to consider not only the public costs, but all costs -- private costs and public. It's all money. It all counts the same. The way to get a handle on costs is through redistribution of public dollars.

Dr. Torres-Gil: Mr. Clayman, how can advocates of the young, aged and poor work more effectively with committees such as this one and that of Mr. Miller to generate the grass roots support and political will needed to protect Americans against these cuts and to make needed reforms that have been suggested this evening?

Mr. Clayman: When the American people speak, Congress generally listens. If you speak, you help make the laws. All of us have grass roots organizations. I know my organization, The National Council of Senior Citizens, makes a special effort to advise our people of the facts about what's going on in Washington and how to make it known to Congress.

You can make your word known to Congress. I know that some of you think that Congressmen don't read letters, that they put no weight at all on the post card. You are wrong. Most of them do -- none of them is unwilling to look at their mail, even by weight if necessary. They cannot ignore the things that come from their own state and from their own districts.

Dr. Torres-Gil: I have one last question to Dr. German before we open the discussion to the floor. As Chairwoman of the Gerontological Health Section of APHA, what suggestions might you have for linking other professional associations representing families and the young such as NASW, the Gerontological Society and other professional associations, with the APHA and other groups interested in multi-generational health issues?

Dr. German: At a meeting of the Gerontological Health Section tonight, we happened to talk about the kinds of bridges we should build with other professional organizations. I think everyone in our Section believes that the practice of gerontology, which includes geriatrics, requires a tremendous amount of interaction among professionals representing social, sociological, educational, and economic issues. Our plans are to try and branch out to the groups that actually deliver care.

As I was listening to the presentations tonight, I was reminded of, and upset by how we have bought the cost cutting issue. We tend to leave behind important questions such as how care is integrated, what good care is, and what it means to the family for a patient to be well cared for. Dr. Kane mentioned housing as an example that can be multiplied in almost every area of functioning. I wish that we could give more attention to these issues at the same time that we fight budget cuts.

I'd like to tell one story that I heard when I was a public health student. A man standing on the bank of a river where people were drowning would swim out and throw one of the people to safety on shore. Then he would go back out immediately and save another person. Someone came along and said, "Listen, half a mile up the bank there is someone throwing these people in. Why don't you go up there and stop them?" The man answered, "I don't have enough time."

Somehow that's what we're doing in trying to finn off all of this legislation. I'm hoping, therefore, from the point of view of our Section, that we won't forget those other extremely important issues in protecting the health care programs of the elderly.

Dr. Torres-Gil: We now invite questions and comments from the floor.

Ann Hardinger: I am a public health nurse in Charlottesville, Virginia and I have a question for Anne Brushwood. I am also working with home health patients and am discovering that many of my clients could cope better as caregivers if they had respite care. Would that be true for your situation?

Anne Brushwood: Yes.

Ann Hardinger: We don't have that in our community, though.

Anne Brushwood: We have a task force working on that right now -- an adult day care for the elderly at risk of institutionalization. We are beginning to work on that in Charlottesville.

Mercedes Burn: Dr. Kane, I work with the United States Consumer Cooperative, a new local group that gives out health care and financial information to seniors in the Washington area. How will the changing role of women impact caregivers and the elderly?

Dr. Kane: You are right to bring up that issue. We are already seeing the effect of the changing roles of women. We didn't used to have so many women in the labor force. Women are in the labor force now not only because it's a good thing, but because incomes are needed and it isn't practical for women to leave the labor force. I think that some of the changes in marriage and divorce patterns will also make a difference in the availability of caregiving. It isn't always clear, for example, which mother-in-law a family should feel a responsibility for. The increased mobility in the society also adds to the problem.

Jane Nessler: I am the Director of an Adult Day Care Center in Seattle, Washington. We have been faced with some biomedical ethical issues which are very pressing in our area right now. Has the Canadian experience given us any insights that we can learn and hopefully profit from?

Dr. Torres-Gil: Our Committee held a hearing a few weeks ago entitled "Death with Dignity." One of our witnesses at that hearing was former Senator Jacob Javits who came in on a life support system arguing that the Congress must begin to look at these issues. Right now there is very little discussion or research in this area. We are just beginning to look at the moral and ethical implications as well as at the political and policy responses that the government should make.

Anne Brushwood: I would like to comment on that too because we did discuss this with my mother. I think it's important that nursing homes, doctors, and other professionals talk to the family members and let them know that there is such a thing as a code that you can ask for. One of my daughters is an emergency room nurse. She has told me a lot of horrible stories about being busy with a 24 year old patient and having to turn her attention to a 103 year old woman brought in while receiving CPR. The families didn't know that you could ask that CPR <u>not</u> be done. As a professional, it is extremely hard when the decisions have to be made.

CONCLUDING REMARKS
Dr. Torres-Gil

In closing, let me first of all thank our panelists, Dr. German, Mrs. Brushwood, Dr. Kane and Mr. Clayman for their insights on the important issue addressed tonight. I also thank the APHA and the Gerontological Health Section for contributing to our discussion and for making this forum possible.

This was the Committee's first attempt to get a handle on the collective effect of the multi-generational issue and the political and policy implications of health care cost containment.

Dealing with this issue will not be easy. We cannot, for example, expect any type of a national health plan next year or the year after -- maybe not even in the next five to eight years. It is the feeling of our Committee, however, that the more you as professionals and families discuss this issue among yourselves and educate the public, the sooner the American public will be willing to make hard decisions and seriously consider increasing tax revenues as the only viable solution to the nation's deficit.

Gramm-Rudman, as many of you know, is a dramatic deficit reduction measure requiring a balanced budget by 1991. If Congress does not make the necessary cuts to achieve this goal, an automatic spending reduction will go into effect.

The Committee and Chairman Roybal believe that we must reduce the deficit, but not by reducing programs like Medicare, Medicaid, SSI, AFDC, and the others that protect vulnerable Americans of all ages.

We believe the real solution to the deficit is to restore many of the tax cuts of 1981, control increases in defense expenditures, and, if necessary, find other revenue sources. Whether or not the Congress is ready to make this type decision has yet to be seen.

The debate over Gramm-Rudman has overshadowed equally fundamental and serious problems as we heard tonight. The affects of DRGs, increases in the Medicare deductible, the lack of a long term care policy, the need to promote more biomedical research on Alzheimer's and other diseases, and the need to respond to multi-generational concerns are all issues which our Committee will be tackling over the next year.

We want to thank you, APHA, and our panelists for allowing us to be with you to begin this process. It may be a long road, but we are certain that, with time, it will lead to positive results.

APPENDIX A

**Committee Staff Analysis of
Impact Of Gramm-Rudman
On Children, Aged And Poor
Updated 1/28/86**

GRAMM-RUDMAN-HOLLINGS THREATENS CUTS RANGING FROM 27% TO AS HIGH AS 44% IN MANY PROGRAMS FOR AMERICA'S CHILDREN, ELDERLY AND POOR BY 1990

MASSIVE 1990 CUTS JEOPARDIZE FUTURE OF HOUSING, MEDICARE, OLDER AMERICANS, EDUCATION, AND HEALTH RESEARCH PROGRAMS

In light of the sequestration reports prepared by the Congressional Budget Office, the Office of Management and Budget, and the General Accounting Office, the staff of the House Select Committee on Aging has re-analyzed the Gramm-Rudman-Hollings Balanced Budget Amendment. The Amendment, part of the debt limit extension legislation, was signed into law (P.L. 99-177) by President Reagan on December 12, 1985.

The Committee staff analysis shows that the Gramm-Rudman-Hollings Amendment will have a major impact on programs for our Nation's elderly, children and poor. The Amendment could **cut from 27 percent to as high as 44 percent** from housing, Medicare, Older Americans programs, Head Start, block grants, education, and other programs aiding children, elderly and poor unless additional revenues or offsetting savings are found. Further, the analysis points out that the source of the deficit problem lies not with programs for the elderly, children and poor but rather with tax reductions and defense spending growth since 1981.

Highlights

Over the past five years, this nation has seen tax reductions and defense spending increases which will equal the 1989 federal deficit of $265 billion and exceed the 1990 deficit of $285 billion by **$38 billion.**

Life support programs for America's children, aged and poor (with the possible exception of Social Security) are severely threatened by Gramm-Rudman-Hollings and could face **cuts of over 26 percent** in 1990 as compared to current services.

The greatest burden -- **over a 44 percent cut** by 1990 -- could fall on the so-called "Category II," non-indexed programs such as housing, Older Americans programs, Head Start, public health programs, health research, education, and many other programs for children, elderly and poor.

Even "Category IA" health programs (Medicare, Veterans health care, community and migrant health centers, Indian health care) could face large reductions. Medicare faces **cuts of about 27 percent** by 1990 as compared to current services.

Background On The Deficit Problem And Its Sources

Based on projections of current law prepared by the nonpartisan Congressional Budget Office, the major sources of our huge deficits are defense spending growth and massive tax reductions in 1981 -- not non-defense discretionary and entitlement spending. Defense spending growth and tax reductions enacted in 1981 will equal the total federal budget deficit beginning in 1989. (See the following chart.) If it weren't for defense spending growth and tax breaks, the budget would not only be balanced by 1990 -- one year earlier than under Gramm-Rudman-Hollings -- but could have a $38 billion surplus.

Deficits, Taxes and Defense

Source: House Select Committee on Aging, 1988, Congressional Budget Office, 1988.

The source of recent deficits lies not with programs for the elderly, children and poor. During the past five years, massive cuts, totaling over $300 billion, have already been made in such programs as Medicare, Medicaid, Food Stamps, housing, and Aid To Families with Dependent Children.

The unfairness of the Gramm-Rudman-Hollings Amendment is seen most clearly in its failure to take into account the main source of the problem -- five years worth of tax cuts and defense growth taken at the expense of cutting needed programs such as Medicare and Medicaid. After all, the negative budgetary impact of recent tax cuts and defense spending growth will total $323 billion in 1990 -- $38 billion more than the 1990 deficit.

Impact Of Gramm-Rudman-Hollings Balanced Budget Amendment *

Life support programs for America's children, elderly, and poor (with the possible exceptions of the exempt programs) are severely threatened by the Gramm-Rudman-Hollings Amendment and could face cuts of more than 26 percent by 1990 as compared to current services. Our analysis shows that the greatest burden -- as much as a 44 percent cut by 1990 -- could fall on housing, Older Americans programs, Medicare, public health programs, health research, Head Start, and many other programs for children, elderly and poor.

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* NOTE: The above Committee staff analysis of the impact of the Gramm-Rudman-Hollings Amendment is based upon the following:

- The most recent interpretations of how it would work if there were excess deficits and the sequestering process were triggered.
- Congressional Budget Office interpretations of which federal budget programs would be exempted from the sequestering process, which programs are uncontrollable, and which of the non-exempt and controllable programs would fall into so-called Categories I, IA or II under sequestering.
- Congressional Budget Office estimates made in February and August 1985 and January 1986.
- The assumption that tax increases will not be a major factor in reducing deficits.

Overall, the total percentage reduction in controllable federal outlays in 1990, as compared to current services outlays, could be 30 percent if there are no additional federal revenues. This percentage represents a $248 billion reduction in Category I, IA, II, and defense outlays from the current services projections for 1990. * In 1986, the reduction is limited to $11.7 billion -- a 4.3 percent reduction for nondefense and 4.9 percent reduction for defense.

The following chart shows that budget cuts over the 1987-90 period could be substantial, especially for the so-called "Category II" programs (including housing, Older Americans programs, Head Start, public health programs, health research (e.g., AIDS, Alzheimer's, Cancer) and many other programs for children, elderly and poor) and Category IA programs (especially Medicare). Category II is hit so consistently and heavily -- over a 44 percent reduction by 1990 -- because it must cover whatever shortfall remains once the other programs have received their cuts.

Sources: House Select Committee on Aging, 1985; Congressional Budget Office, 1985.

Gramm-Rudman-Holling Sequestration Categories:

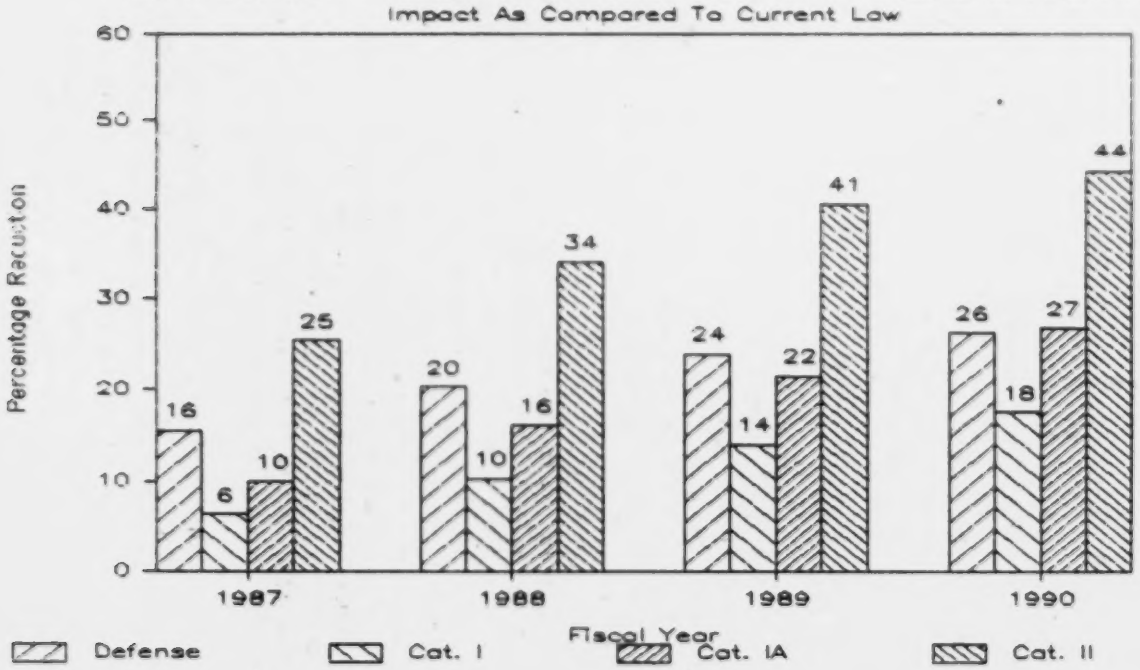
Defense (At one time, defense was part of Category II.)

Category I: Automatic spending increase programs such as federal and military retirement, etc.

Category IA: Medicare, Veterans medical care, community and migrant health centers, Indian health care.

Category II: Other controllable expenditures (those without automatic spending increases) such as housing, block grants, Older Americans programs, education, etc.

CRAMM—RUDMAN OUTLAY REDUCTIONS



As compared to current services, Category II non-indexed programs could be hit with the biggest percentage reductions if the Gramm-Rudman-Hollings sequestering process is triggered and no revenues are added. For 1986, Category II represents just over $100 billion in programs, including housing, Older Americans programs, social services, transportation, and block grants. A 44 percent reduction of non-indexed programs by 1990 would mean a tremendous loss to those who depend on programs like housing, elderly meal programs and social services. This would translate into over $94 billion in cuts below current services estimates for 1990.

In the case of Medicare (in Category IA with community and migrant health centers, Indian health services, and Veterans health care), the pressures of Gramm-Rudman-Hollings could result in a 27 percent reduction by 1990 as compared to current services. This reduction could translate into Medicare cuts of about $32 billion in 1990.

In addition to this loss of $32 billion to Medicare in 1990, yearly payment adjustments to health care providers for Medicare could be completely eliminated for most, if not all, previous years as a result of continuing deficit shortfalls. These cuts are likely in spite of the fact that Medicare is subject to sequestering cuts of only one or two percent in any given year. The remainder of the Medicare cuts are expected to come through administrative or legislative (reconciliation) action resulting from the pressure to balance the budget and protect other programs, including defense.

Federal retirement programs (Category I) are also not spared from the Gramm-Rudman-Hollings sequestering. Federal retirees could lose their COLAs for most if not all of the next six years. As a result, payments to federal retirees could be 18 percent less than they could have expected under current law.

Under Gramm-Rudman-Hollings, defense faces cuts in 1990 of about 26 percent as compared to current services projections. The percentage may vary for particular defense programs depending on Presidential decisions about contracts. While these cuts are more than the cuts to Category I programs, the percentage reduction for defense is substantially less than for Category II programs.

Though several programs (Social Security, SSI, Medicaid, Veterans pension and compensation, AFDC, food stamps, child nutrition, WIC) are exempted from Gramm-Rudman-Hollings sequestering, the pressures of balancing the budget make the exempt programs major targets as well. Social Security may be the one exception since benefit payments are protected from cuts in the reconciliation process. However, Social Security staff and offices are not protected and are subject to Category II level cuts.

Conclusion

Over the past five years, lower taxes and higher defense spending were pushed while programs for the elderly, children and poor were reduced. Even without Gramm-Rudman-Hollings, past actions will slash a total of $304 billion between 1982 and 1990 from federal entitlement programs, such as Medicare and Medicaid, and other programs for the aged, young and impoverished. For this same nine year period, federal budget deficits will be increased by more than $1,500 billion due to the cumulative impact of tax reductions and defense spending growth.

We have already seen massive reductions in the very same human service programs targeted by the Gramm-Rudman-Hollings Amendment. The Aging Committee's analysis shows that this Amendment could **cut more than 26 percent** from many programs for America's elderly, children, and poor by 1990. Medicare alone could face cuts of **over $32 billion in 1990**. Under Gramm-Rudman-Hollings, Category II programs, including housing and Older Americans programs, face the deepest cuts -- **over a 44 percent cut as compared to current estimates.**

While this Committee analysis begins to answer questions about the depth of the Gramm-Rudman-Hollings cuts for federal programs, we must now take the next step and assess the personal impact that Gramm-Rudman-Hollings will have on vulnerable Americans of all ages.

Afterword

For further information on the Gramm-Rudman-Hollings Amendment and its impact on elderly, children and poor, please contact Gary Christopherson or Anthony Knettel at the House Select Committee on Aging, Room 712, Annex #1, Washington, D.C. 20515; Phone: (202) 226-3375.

APPENDIX B

Preview of Forthcoming Report "The Common Stake: The Interdependence Of Generations In An Aging Society"

Prepared By The Gerontological Society of America

The aging of our society is both a success story and a challenge!

More people are living longer. The quality of life for increasing numbers of elderly people is better than that for previous generations. Much of this success can be attributed to public and private investments, directed at all ages, in successful research, education and public health programs, successful public policies, and economic growth. In short, the increased probability of reaching old age and the generally improving quality of life in old age are a result of the success of the sum of investments and advances made by past and present generations in addressing problems across the life course.

Yet even while acknowledging the advances made, we also must recognize that millions of older people continue to live in or near poverty and continue to be afflicted with debilitating chronic illnesses. Further, the prevalence of poverty, chronic illness and disability peak in the oldest age group. Those 85 and over also are the fastest growing segment of our population. As long as our society continues to value the lives of all individuals, the Nation will be challenged to find ways to ensure the economic well-being of the elderly, to reduce the effects of chronic illnesses, and to provide humane care to those who require assistance or care on a continuing basis.

To complicate the situation, the challenge is occurring at a time when the political mood has preferred to deal with a serious federal deficit problem primarily by cuts in federal domestic programs rather than by increases in taxation and/or reductions in the growth of

the defense budget. At the same time, the poverty rates for children are very high, and federal, state and local programs designed to respond to the needs of poor children and their families have experienced disproportionate share of budget cuts in recent years. It is also a moment when the oldest members of the baby boom generation are but 25 years from retirement. Whatever the costs to individuals, families, and government of meeting the challenge might have been with a more normal increase in the number of elderly, the transition of the baby boom generation into retirement will further increase these costs.

The Purpose Of The GSA Report

This is the context in which an approach to assessing social policies based on a loosely defined concept of "intergenerational equity" has emerged. This approach frames policy questions in terms of competition among generations over scarce resources, using narrow measures of transfers of selected resources between generations as a basis for determining the "fairness" of public policies and for making changes in public policies.

While seemingly neutral in approach, and possessing an intuitive appeal (Who can be against fairness?) this approach, whether by design or inadvertence, carries with it a very pessimistic view about the implications of an aging society which leads to particular policy goals and prescriptions. Also, with some frequency, the approach is being used to justify charges that the elderly are receiving an inequitable share of public resources and that this inequity is leading to conflict between generations.

The tone and character of the debate being generated by this approach prompted the decision to prepare this report. The outcome of the debate could determine how society reacts to the challenge of an aging society, from policies affecting children to policies affecting older persons, from the shape of research agendas to the design of income maintenance, educational, social service, and health care programs.

Further, an appreciation of the basic values which have driven social policies in the past, an understanding that each generation contributes to and benefits from social progress, and an awareness of the common stake in family efforts and programs which respond to the needs of people of all ages, seem in danger of being forgotten or ignored amid the emotional rhetoric surrounding this debate.

For these reasons, it is important to understand why, in an interdependent and aging society, all generations have a common stake in intergenerational transfers which assist individuals and families in responding to needs existing at all points across the life course -- including: 1) private intergenerational transfers (e.g., assistance provided within families); 2) intergenerational transfers that are the result of public policy (e.g., Social Security, education); and 3) societal intergenerational transfers (e.g., economic growth, new knowledge). The report discusses how policies directed at one age group affect all others at any given point in time and over time as these groups age; and emphasizes that intergenerational transfers are more than simply government programs.

While recognizing the challenge of an aging society, the point of view presented in this report is more optimistic about the nation's ability to respond to this challenge without compromising the needs of citizens, regardless of age.

The purpose of this report, then, is not to advocate particular policies for meeting the challenge of an aging society. Rather, the intent is to: 1) note the importance of thinking about society and the life course as a whole; 2) discuss the stake that all generations have in private and public intergenerational transfers; 3) stress the importance of all levels of government sharing the burden with individuals and families of meeting the needs of persons of all ages; and 4) identify the implications and flaws of an approach to policy that is based on a narrow interpretation of "equity between generations" and which frames policy issues in terms of competition and conflict between generations.

Organization Of The GSA Report

The chapters of the report discuss:

- The basis of the view that all generations have a common stake in private and public intergenerational transfers which respond to needs at all points across the life course.
- The common stake in a private intergenerational transfer -- the giving and receiving of care within the context of the family.
- The common stake in an intergenerational transfer that is the result of public policy -- Social Security.
- The common stake in a societal intergenerational transfer -- public and private investments in research on aging.
- The stake of advocates for the elderly, and the elderly themselves, in policies for children.
- The stake of each age group in social policies which will shape their well-being throughout life.
- The research needed to better understand intergenerational relations and the life course in an aging society.
- The pitfalls of using the "intergenerational inequity approach" as a basis for policy.
- The implications of applying an understanding of the common stake to the policy process.

Afterword

The Gerontological Society of America's report is the first in a series of reports on emerging issues in aging. Financial support for the development of this new program has been provided by the AARP Andrus Foundation, the Allied Corporation, the John A. Hartford Foundation and the National Institute on Aging (for the research agenda). The opinions expressed in this report are those of the authors and do not necessarily represent positions of the Gerontological Society, those of organizations providing funding, or those of individuals and organizations associated with the program through involvement on its Steering Committee and National Advisory Committee.

For further information, please contact Linda Harootyan, Eric Kingson or Barbara Hirshorn at The Gerontological Society of America, 1411 K Street, N.W., Washington, D.C. 20005; Phone (202) 393-1411.